#### WORK-IN-PROGRESS AND LESSONS LEARNED

### Using Talanoa in Community-Based Research with Australian Pacific Islander Women with Type 2 Diabetes

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#### ABSTRACT

Background: Type 2 diabetes is a significant public health problem and Australian Pacific Islander (API) women and their communities are experiencing a higher burden of morbidity and mortality from the disease. Despite this higher burden there are few initiatives that are culturally tailored to improve prevention and management.

Objectives: We used talanoa, a community-based research methodology to build capacity with API women living in Queensland and to develop culturally relevant methods of information sharing and knowledge building.

Methods: The partnership informed the co-design and conduct of research using a talanoa methodology framework.

Lessons learned: Talanoa was used in negotiating the research partnership, setting up a steering committee, developing protocols for community engagement, collecting and co-constructing knowledge and disseminating community outcomes.

Conclusion: The community-academia partnership and the participatory processes using talanoa facilitated dialogue and engagement to promote diabetes prevention and management for API communities.

**KEYWORDS:** Pacific research, Talanoa, Community-based participatory research, Australian Pacific Islander women, Diabetes self-management, Type 2 diabetes

#### BACKGROUND

Australia has the largest Pacific Islander diaspora second only to New Zealand. Despite being administratively classified as Pacific Islanders, the Australian Pacific Islander (API) communities in Queensland are heterogeneous with diverse cultures, languages and religions. The communities include first, second, and third or more generations predominantly originating from three Western Pacific groups: Micronesia, Melanesia and Polynesia<sup>1, 2</sup>. Many maintain strong ties with their Pacific home nations and thus preserve their cultural traditions including collectivism that places greater emphasis on spirituality, family, and community. Within collectivist cultures communal responsibility, interdependence and cooperation are valued and the needs of the group take precedence over those of individual members. The social network is the primary source of information and harmony is essential for communication.<sup>3, 4</sup> This creates a disconnect in countries like Australia where responsibility for health sits with the individual, and where communication is more direct and information dissemination less reliant on social networks. The individualistic approach is embedded in the concept of person-centred care which is the corner-stone of chronic disease management<sup>5, 6</sup>

Type 2 diabetes is a particular issue for API communities with APIs having poorer health outcomes generally compared to the general Australian population <sup>7-9</sup> and are at two-to-four times greater risk of hospitalisation and preventable deaths from diabetes-related conditions <sup>10</sup>. Many API women, in particular, do not use support programs such as education and healthcare resources which are deemed critical in the prevention and self-management of diabetes <sup>10</sup> The question, therefore, is how can we work with API communities to build more effective and culturally responsive approaches to diabetes prevention and management. This paper reports on research that used

community-based participatory action and talanoa, familiar and culturally sensitive methods of information-sharing, data collection and knowledge building for the development of an approach to support the prevention and management of type 2 diabetes among API women living in Queensland.

#### **Community-Academic Partnership**

Establishing meaningful and respectful community partnerships is essential to a participatory approach. In this case, a partnership was established in 2013 between the Pasifika Women's Alliance (PWA) (a culturally diverse not-for-profit network representing 22 API communities), Queensland University of Technology (QUT) (Academia), Diabetes Queensland (non-government) and Children's Health Queensland Good Start Program (GSP) (government). The PWA was the lead agency as they had identified type 2 diabetes as a key issue as part of their strategic vision: '*Healthier and Stronger Families*'<sup>11</sup>. The Alliance also identified high levels of sensitivity around diabetes in the API communities (where members were reluctant to talk openly about their condition) and limited diabetes/health data to leverage funding and action. The lead researcher (first author) brokered the partnership and provided a link between all partners. As a Fijian-Australian and a member of PWA she had well-established connections with the API communities in Queensland, had worked for and was undertaking her PhD with the university, and had secured funding from the peak diabetes organisation.

#### **METHODS**

#### **Study Design**

The research was undertaken between December 2012 – May 2017 and engaged the PWA as co-researchers in all stages from conception of the research to identifying training needs for co-researchers, providing cultural advice critical to the implementation of the diabetes research as well as undertaking data collection, analysis, finalising recommendations and disseminating research findings. A Steering Committee (SC) was established following a ten-month period of engagement by the lead researcher with API communities in formulating the diabetes research project..

#### Set up of Steering Committee (SC)

The SC consisted the lead researcher, ten PWA members who represented respective API community groups, members of the community, academia and government and non-government organisations. This makeup ensured ethically cultural and respectful research was conducted that integrated community knowledge and had direct community benefit. Through the PWA, the SC members were sent formal invitations explaining the project objectives, roles and expectations of the committee and their involvement. The first meeting, co-chaired by the lead researcher and PWA president, was convened in July 2013 to discuss project objectives and to co-develop terms of reference (TOR) (Figure 1).



Figure 1. Steering committee meeting held on the 22<sup>nd</sup> July 2013 at Inala Community Hall Photographer: Pasifika Women's Alliance (PWA- 12/06/2013). Used with permission.

The TOR articulated the partnership mission statement, roles and duties of the SC and operating procedures such as number of meetings, feedback processes, transparency of information sharing, confidentiality and code of conduct. Both SC and PWA members were trained as co-researchers. The SC was responsible for co-developing and implementing diabetes initiatives such as diabetes forums in 2013, 2014 and 2016 as well as formulating partnership agreements and procedures. The agenda was set by the SC with the academic partners providing the evidence-base, underpinning theoretical and methodological frameworks as well as ethics support. Diabetes Queensland and GSP facilitated access to resources and best practice guidelines for diabetes prevention and management.

#### The Talanoa Framework

The development of the approach to support the prevention and management of type 2 diabetes was underpinned by talanoa. Grounded in oratory traditions, talanoa is recognised in many Pacific nations, including Fiji, Tonga, Tokelau and Samoa, as a way of sharing information, learning, relating and creating shared meaning through reciprocal interactions in a culturally respectful space <sup>12, 13</sup>. Talanoa uses storytelling or conversation through a relationally critical oratory<sup>14</sup>. Telling one's story implies that culture is embodied in the construction of a story and that significant cultural factors emerge from that story<sup>15</sup>. Talanoa involves a deep engagement and depends upon interpretation of what is said and unsaid through the cultural lens of those telling stories <sup>14</sup> Talanoa can be compared to other Indigenous methodologies such as yarning for Australian Indigenous peoples<sup>16</sup>, talking-story for Native Hawaiians<sup>17, 18</sup>; and sharing or talking circles for the First Nations peoples of Canada<sup>1</sup> and the United States<sup>19 20</sup>.

Talanoa is carried out with an understanding that local acknowledgement systems are perpetually negotiated within cultural spaces that are continually evolving, spontaneous and moving<sup>14</sup>. According to Tecun et al.<sup>14</sup> talanoa ontology is grounded within the principles of having mana or spiritual connection which relates to sacred power or supernatural transformation; creating noa or finding a balance in terms of power relationship (equilibrium); and respecting space that is sacred or taboo. These ontological concepts allow people to make connections through genealogy, ancestry or place so that they can enter deeper into critical discussions<sup>14, 21</sup> and where communal relationships are built on shared values and community harmony<sup>22, 23</sup>. The centrality of talanoa is

<sup>&</sup>lt;sup>1</sup> First Nations People, Métis and Inuit

its Pacific knowledge systems and its application in research permits partnership with Pacific communities to undertake culturally safe research with Pacific peoples<sup>24</sup>.

#### **Operationalisation of the Talanoa Framework and Guiding Principles**

A framework and set of principles for ongoing engagement with communities was developed using the PWA logo <sup>2</sup> which informed the iterative community-based talanoa process. The talanoa framework, drawn from the work of Halapua <sup>13</sup> and Vaioleti <sup>12</sup>, is based on community-based participatory research principles (CBPR)<sup>25, 26</sup> where each step of CBPR cycle is deconstructed using talanoa as the lens as shown in Figure 2.

<sup>&</sup>lt;sup>2</sup> The hibiscus emblem for Pasifika Women represents a collective network of culturally diverse Australian Pacific Islander women in Queensland with a shared vision of promoting health and wellness of Pacific families and communities in Australia.

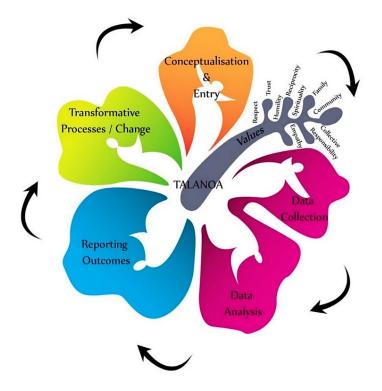


Figure 2. The talanoa framework within a community- based participatory research informing the diabetes self-management of Australian Pacific Islander women with type 2 diabetes. The hibiscus emblem for Pasifika Women's Alliances (PWA) represents a collective network of culturally diverse Australian Pacific Islander women in Queensland with a shared vision of promoting health and wellness of Pacific families and communities in Australia.

Figure 3 describes the steps undertaken to negotiate and develop the framework. The SCguided the process drawing on diabetes forums to define the talanoa context, develop protocols for engagement with API communities and inform data collection, analysis and partnership outcomes. After several iterations, the final framework was endorsed by the SC and applied in the diabetes research.

PWA identified diabetes as priority concern for API women and their families in Queensland.

PWA engages with lead researcher (QUT) who brokers community-academic partnership.

Steering Committee established to include all stakeholders

Steering Committee use talanoa to develop terms of references (TOR) and general principles, and discuss principles of engagement with API communities.

Steering Committee finalise and endorse talanoa framework contextualising CBPR and talanoa principles.

The framework guides the co-design and implementation of the diabetes forums including community engagement, recruitment, developing tools such as surveys and talanoa discussion guides used at the diabetes forums, data collection, analysis and disseminating findings and informing community outcomes.

Figure 3. Steps with developing the talanoa framework.

#### **Recruitment and Engagement of API communities**

Recruitment involved invitations to API community members and organisational representatives and API and non-API health professionals; advertisements on local ethnic radio, newsletters and social media such as Facebook. Community flyers, co-developed with the SC were circulated at community events such as Pasifika International Women's Day, Pasifika Independence Day, Multicultural Festivals. Throughout the study, snowballing enabled further identification and recruitment of specific community members including API women with type 2 diabetes and stakeholders working with API communities in Queensland <sup>27</sup>.

#### **Pasifika Diabetes Forums**

Three community-led Pasifika diabetes forums resulted from the community-academia partnership. The first two, in 2013 (held at Inala Community Hall, South west of Brisbane) and in 2014 (held at Chermside Uniting Church, North Side of Brisbane), were for API women. A third forum in 2016 (held at QUT) included whole-of-community (men, women and children). The forums were used for data collection, meaning co-construction and information generation and sharing using talanoa. They provided a culturally safe space (vā) to promote diabetes prevention and management and inform the development of community-based solutions to improve diabetes health outcomes of APIs in Queensland. The 2013, 2014 and 2016 were attended by 60 API women, 120 API women and 380 API community members respectively (Table 1).

The 2013 forum finalised the framework and allowed for the generation of preliminary data using talanoa processes. Further data was generated during the 2014 forum and feedback was provided on the talanoa processes from the community women. This forum also gave rise to

recommendations to trial diabetes health check passports and to conduct digital narratives of community members with type 2 diabetes. The 2016 forum saw the implementation of the principles developed in previous forums in launching the health check passports and the digital narratives.

Table 1Summary of data collection using talanoa

Data collection using talanoa	Purpose	Number of participants and/or events
Community Stakeholders (2012 - 2013)	Community engagement to establish meaningful relationship and co-develop cultural protocols	<ul><li>21 Stakeholders</li><li>7 Community Events</li></ul>
4 Community Leaders Meetings (2012 -2014)	Explore diabetes and co-develop diabetes forums using community strategies & methods	41 Community leaders
API women with type 2 diabetes (2013 – 2014)	Co-develop narratives of lived experiences with type 2 diabetes	10 women with type 2 diabetes
3 Pasifika Diabetes Forums (2013, 2014, 2016)	Implement forums to create a safe space for talanoa discussions, collect data, deliver education sessions and conduct health checks.	60 women at 2013 forum 120 women at 2014 forum 380 Community members at 2016 forum
Steering Committee Meetings (2013- 2016)	Co-design, co-develop and oversee implementation of the project, talanoa framework and community engagement protocols	15 members

#### **Doing Talanoa**

Talanoa occurred formally and informally depending on context and whether the goal was to gather information, discuss community protocols, or build rapport <sup>23, 28</sup>. The approach varied from one-to-one interactions to group discussions and were informal when building rapport with

community members and more formal when talking with health service providers or community leaders. One-to-one talanoa took place in women's homes, at community events and public places.

Prior to each talanoa (whether formal or informal), participants were provided with information detailing the study purpose, how the talanoa would be conducted and confidentiality and consent. Project materials, including participant information and consent form and promotional flyers were discussed to ensure that the study was ethical, respectful and culturally safe. While most talanoa were audio-recorded less formal impromptu talanoa were scribed by the lead researcher in note format. All audio-recorded talanoa were transcribed and emailed or posted to those participants who agreed to review their interviews. Transcribed data and researchers' reflections and meeting notes were used for analysis.

#### Talanoa with Community Stakeholders

Talanoa with API community leaders, health professionals and community and government representatives were important in the early phase of consultations to gain access to API communities and to explore community engagement processes and cultural protocols using CBPR, community perceptions on diabetes and potential networks and participants for in-depth talanoa.

#### Talanoa discussions at Diabetes Forums

Talanoa at the forums provided community perspectives on potential strategies to address diabetes stigma and to develop a community-centred approach to diabetes care. Although similar to conventional focus groups, the talanoa created a cultural space in a structured setting with a

specific agenda. The group discussions were facilitated by co-researchers who received training on how to conduct respectful discussions using talanoa <sup>22</sup> and on ethics and consent processes, moderation sing talanoa techniques, note-taking and cultural preparedness. While a topic guide provided direction, the discussions were open and conversational, allowing participants to freely share their perspectives. Separate talanoa discussions for men and women in the 2016 forum was important in acknowledging men's and women's businesses when discussing diabetes and gender sensitivities. Ideas generated during the discussions were recorded on large pieces of paper and presented by each group. The sessions ran for one and half hours, were audio-recorded and transcribed for analysis.

#### **Collecting Health Data at Diabetes Forums**

As requested by the SC, data on demographics, health status and diabetes were collected at the diabetes forums. According to Smith <sup>29</sup>, implementing epidemiological surveys in Indigenous populations requires deconstructing underlying assumptions of empirical instruments based on positivist views. Using talanoa participatory processes allowed these assumptions to be deconstructed and ensured inclusion of a cultural orientation, space and time to collect data <sup>30</sup>. The SC provided input into what information was to be collected on health, diabetes and demographics as adapted from the National Health Survey (for Australian population).

#### In-depth talanoa with API women with type 2 diabetes

API women with type 2 types, identified through PWA networks and diabetes forums, explored cultural and community context for diabetes self-management. The conversations were

many and were conducted by the lead researcher often in various social contexts around food preparation, sharing of meals and participating in community life. The audio-recording and lead researcher's notes provided research context to the talanoa.

#### Data analysis

The co-construction of knowledge was informed by an interpretive constructionist lens <sup>31, 32</sup> using the developed talanoa framework. From this perspective a reality is co-constructed from ongoing conversations and interactions where social meanings are interpreted by both the participants and researcher <sup>31</sup>. Initial analysis was conducted during data generation was iterative where notes, transcribed data and emergent ideas were discussed with the SC and PWA members. The SC and PWA members and lead researcher read the transcripts and undertook open and focused coding to construct concepts <sup>31, 33</sup>. Coded transcripts and preliminary concepts were reviewed and refined after re-reading the entire data set <sup>31</sup>. The analysis process was culturally contextualized and included data on family, community and spirituality<sup>34, 35</sup>.

Agreement on labelling of concepts was reached through discussions with the SC and PWA members. Any inconsistencies were further reviewed and validated with the SC and PWA members. Talanoa were undertaken until a shared meaning and consensus was reached <sup>36</sup>. Research findings were presented to PWA and the API communities at the PWA network and Community Leaders meetings and to the SC in various locations such as the Pasifika House, church and community halls. A final written report with recommendations was submitted to the SC for endorsement and circulated to all partnering stakeholders.

#### **RESULTS AND LESSONS LEARNED**

Table 1 depicts the talanoa and data collection for this study which included twenty-one oneto-one talanoa with key stakeholders, seven community events, four community leaders meetings attended by the lead researcher and ten in-depth talanoa with API women with type 2 diabetes.

#### Co-constructing knowledge using talanoa

The process of talanoa began with building and strengthening authentic relationships with API communities<sup>37</sup>.Conceptually, talanoa explains the development of a relational space (vā), and refers to the inter-relational space and the underpinning spiritual context which enables partnerships to be developed and maintained in ways excluded by Western relational constructs. For Pacific peoples, creating this space, where meaningful relationships can be established between individuals, groups, researchers and partners is vitally important in developing respectful research with API communities<sup>15</sup>. The use of safe cultural learning spaces such as Pasifika House to conduct meetings, and community halls or churches and homes of API women for in-depth talanoa, allowed for exchanges of ideas. <sup>35, 38</sup>.

The API women with type 2 diabetes shared their narratives shaped by their values, personal experiences, knowledge levels and cultural practices surrounding diabetes. They understood the importance of developing a shared sense of ownership that contributed to supporting and honouring one another's voices. In many instances, this required the researcher to watch and wait patiently as the interpretation and representations of the patterns emerged through talanoa interactions. While the interpretation accorded respect for Pacific values and worldviews, the information shared between the researcher and the women enabled a cultural synthesis on the different perspectives of the talanoa on diabetes self-management <sup>24, 31</sup>. The women were given time to tell their diabetes stories which

promoted meaningful interactions and active participation in the safe environment of their trusted community. An example of a response from one participant exemplifies the information elicited:

My mother has diabetes. I have pre-diabetes and I need to look after myself. Having grown up thinking big is beautiful, it has been difficult for me to change. My cultural perceptions and Tongan heritage allow me to think BIG is beautiful.... As the only daughter and the eldest, I am hierarchically highly positioned in the family, so I was encouraged to eat most with the choices of the best. I could eat as much fatty and rich foods as I pleased. This is my birthright.

Empathy was central to talanoa interactions enabling researchers and the participants to understand each other's worldviews, processes and outcomes that would benefit both parties <sup>37</sup>. The women were able to 'voice' their experiences and develop their own learning, which many of the API women with type 2 diabetes described as 'empowering in having control of their and their family's health'. The women were drivers of the diabetes forums and participated in research skills and mentoring training that enabled them to collect health data within their cultural spaces. The women shared their skills and knowledge to promote diabetes awareness in their communities.

The academia-community partnership through the diabetes forums emphasised knowledge translation which again was central to the participatory research processes using talanoa. The co-researchers with the support from academia learned how to develop and conduct surveys or talanoa discussions in a culturally safe manner with their communities. The participatory process also reflected on the importance of a community-centred approach to diabetes care and the need to collaborate with mainstream health care services such as Diabetes Queensland and the GSP. The community was able to develop trust in and engage with

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mainstream health providers at the forums, thus promoting awareness in the API community on the importance of utilising these services for diabetes care.

#### DISCUSSION

Talanoa in the Australian context recognises the interactions and communications between APIs and non-APIs in a cross-cultural space with prominence given to community protocols, language and cultural respect when engaging with API communities. Forming partnerships between communities and mainstream health organisations requires long term engagement to build trust and rapport and includes a range of cross-cultural communication styles and interactions ensuring a positive collaborative outcome <sup>36, 39</sup>. Thus, talanoa encounters require lengthy periods of community engagement which may not accord with mainstream research methods and institutional or funding requirements. In this research, the initial engagement with the community over a ten month period allowed lengthy discussions to occur in order to establish reciprocity, build trust, and make connections <sup>18,40</sup>. The absence of a defined timeline, often criticized in mainstream research, is culturally respectful where both researchers and community members are equal contributors to the decision-making processes that contribute to knowledge building<sup>41, 42</sup>. Within the research space, the giving of time in the exchange process of sharing of information and the construction of meaning about diabetes authenticated the talanoa process <sup>43,</sup> <sup>44</sup>. Vaioleti, describes this process as trustworthy, relevant and reliable because the researcher and the community members are both elemental contributors to the decision-making processes and crucial benefactors of the knowledge. <sup>15, 35</sup>.

In any talanoa context, cultural awareness and community protocols are paramount for non-Pacific researchers when engaging with API communities. Such protocols need to be clearly defined and articulated so that there is methodological rigour and research reliability when using talanoa in a Pacific research context <sup>23</sup>. This study adapted and integrated university ethics into the talanoa process.

Talanoa processes are fundamentally about generating a shared meaning and understanding and arriving at collectivist solutions that are community-generated and have community impact. More mainstream approaches that validate the responses of individuals and person-centred care may underestimate the value of talanoa as not only a tool for data collection but as a tool for improving the capacity of communities to undertaken more optimal diabetes prevention and management.

#### NEXT STEPS

This research has resulted in the development and dissemination of a 'Pasifika Women's Diabetes Wellness eProgram' which used the talanoa framework and includes the diabetes passport and digital narratives. The program is about to be piloted in the communities in South-East Queensland. In addition, the PWA is using the framework to engage with other Pacific researchers on issues relevant to the community, the most recent being "Feeding our Mana" which is an exploration of household food insecurity and access to healthy cultural foods.

#### CONCLUSION

Our use of talanoa to generate data about and responses to the prevention and management of type 2 diabetes among API has identified a number of key considerations. Talanoa can be applied across all aspects of the research process including establishing community-academia partnerships, negotiating the research agenda that is mutually beneficial to the community, identifying engagement strategies that ensure community protocols are observed, adapting tools to collect and analyse data and engaging community members in co-developing initiatives or solutions. Talanoa facilitates and strengthens community engagement, maximises participation and ensures sharing of information and co-creation of knowledge in an effort to influence social change. The emphasis on cultural safety, partnership with API women with type 2 diabetes and social equity was equally important to promoting diabetes prevention and management in the communities.

The methodological approach explored above has wider applications for planning and developing culturally appropriate diabetes health-promotion strategies and community-based interventions for API communities. It informs research processes using Pacific Indigenous methods for collectivist communities that can be applied across other Pacific communities in translating better health outcomes.

#### Glossary

vanua	refers to the land, its people and their ongoing relationships, Also known as fonua in	
	Tonga, fanua in Samoa, whenua in Maori and enua in the Cook Islands <sup>15</sup>	
Radini	a minister's wife in Fijian	
sulu-jaba	traditional dress worn by Pasifika women	
ta'ovala	the waist mat or tapa wrapped around traditional dress	
talanoa	is a form of communication used daily by Pacific peoples.	
Talatala	refers to a church minister in Fijian	
vā	means relational or sacred space	

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#### **Declaration of conflicting interests**

All authors fulfil the criteria for authorship by continuing from the conception, design, process, analysis and write up of this article. All authors read and approved the final manuscript.

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#### Ethics

Approval to conduct this project, as part of the PhD study, was obtained from the Queensland University of Technology Human Research and Ethics Committee (Approval number: 13000000229). The PhD research was conducted between December 2012 – 2017.

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